The NHS Calderdale CCG and NHS Kirklees CCG
Learning Disabilities Mortality Review Programme (LeDeR)
Annual report 2020 – 2021

Report prepared by: Clare Robinson: Head of Nursing and Safeguarding

Executive Lead: Penny Woodhead; Chief Nursing and Quality Officer

Report approved by: The Quality Committee in NHS Kirklees CCG and Quality finance and Performance Committee NHS Calderdale CCG

Executive Summary

Health inequalities between different population groups have been well documented, including the inequalities faced by people with learning disabilities.

The Learning Disabilities Mortality Review (LeDeR) programme, commissioned by NHSE, was established to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement initiatives.

During the past 12 months NHS Calderdale CCG and NHS Kirklees CCG has worked in partnership with key stakeholders to deliver the LeDeR programme and the reviews

Each of the LeDeR reviews describes a human story and we recognise the commitment and hard work of the Reviewers to not only complete the reviews, but to also tell those individual stories so that we can learn about those individuals' experiences and continue to drive any required improvement in the quality of health and care services . For this reason, we have included four pen portraits this year of people who sadly died and a LeDeR review was undertaken. The pen portrait details have been taken directly from LeDeR reviews, however to protect individual identity names have been changed and explicit details that might identify an individual have been omitted.

This joint CCG's annual report of the Learning Disabilities Mortality Review (LeDeR) Programme presents information about the deaths of people with learning disabilities who were reported into the programme, alongside local actions that are underway to address learning by Learning Disability (LD) commissioners and Transforming Care Leads.

The purpose is to provide an overview of the programme delivery through between 1st April 2020 and 31st March 2021.

The report also provides key information regarding any areas of learning from the reviews and presents an overview of the work of Learning Disability Commissioning Leads to transform care for people with a Learning Disability who live in Calderdale or Kirklees. For example in response by NHSE/I to the learning from the national review of people who died from Covid 19 and had LD, locally a number of actions were undertake including:

- In both Calderdale and Kirklees all homes for people with LD have a lead GP and care coordinator that is working closely with the home to ensure reactive and proactive needs are being met in a timely manner
- The joint CCG's Quality Team have offered supportive training sessions to Care homes in Calderdale and Kirklees in how to recognise signs of deterioration in their residents through the use of 'Soft signs'. This training supports the Care Home staff who know individuals best, what to look for and when to seek refer yp relevant healthcare professionals to access early clinical review

Other Transforming Care work over the last year has included a project to develop and implement an enhanced all age Dynamic Risk Register for people with Autism, to ensure any change or potential risks of an individual's Autism or Mental Health is identified at an early stage and that interventions are provided by the Local Community Teams and reviewed regularly and reducing the risk of hospital admission.

Contents

Executive Summary 2

Other Transforming Care work over the last year 3

Pen Portraits 6

1.0 Introduction and Background 8

2.0 Purpose of this report 8

3.0 Delivering the LeDeR Programme Locally 9

3.1 Governance arrangements for the LeDeR programme 9

3.4 Linking LeDeR cases to statutory processes 10

3.5 Challenges to delivering the reviews in the last year 10

3.6 West Yorkshire LAC approach 11

4.0 LeDeR reviews locally 12

4.1 The number of Local Cases 12

4.2 Completed LeDeR reviews in the last year 13

4.3 Demographics for cases 13

4.3.1 Gender 13

4.3.2 Ages of those who died 13

4.4 Key information about the Death 14

4.4.1 Cause of Death 14

4.4.2 Multi morbidity 14

4.4.3 Month of death 15

4.4.4 Place of Death 16

4.4.5 End of Life Care planning 16

4.5 Finding themes 16

4.5.1 Overall assessment of care 16

4.5.2 Positive themes 17

4.5.3 Learning from local cases 19

5.0 Taking forward learning from cases 20

5.1 National Learning from deaths due to Covid 20
5.1.2 Local Actions to respond to LeDeR learning 20
Priority 1: Identifying deterioration in health 20
Priority 2: DNACPR and learning disability as a cause of death 23
Priority 3: Diagnostic overshadowing 24
Priority 4: Reasonable Adjustments 25
6.0 Other Transforming Care work over the last year 26
7.0 Future planning and Priorities for the LeDeR Programme 28
7.1 New NHSE LeDeR Policy 28
7.1.3 LeDeR Reviewers 29
7.1.4 Quality Assuring LeDeR reviews and actions 29
7.1.5 Delivery expectations 29
7.2 Priorities for the coming year: Delivering the new LeDeR Policy 30
Appendix A Part 1: Flowchart from notification to learning: process current 31
Appendix A Part 2: Flowchart from notification to learning 32

Pen Portraits

Introducing Jane:

Jane was a 57 year old lady who had lived locally in a Residential Care Home before her death. She preferred to be as independent as she could be but needed the reassurance and encouragement from the staff in the Home for example, she was able to administer her own medications from a medicine box that was prepared by the staff and kept in her bedroom. Jane told staff in the Home that she saw herself as very happy, rarely angry and only feeling sad over the death of her parents. Whilst she was reluctant to go out from the Home and needed the support of others to do so, she did enjoy living with others, and liked to help in the Care Home such as setting the tables at meal times. She was though very determined about what she would and would not do and would tell staff her preferences for example, despite having poor eyesight, she did not like to wear her glasses no matter how much she was encouraged. But Jane did particularly like the craft activities being undertaken in the Home as well as undertaking some crafts on her own – especially her knitting.

Jane became very ill suddenly, and after being admitted to hospital and all care given she very sadly died of Covid 19.

Introducing Peter:

Peter was a 68 year old man who had been living in a Residential Care Home for a number of years. Whilst Peter did not have the ability to make all his own decisions and had a Deprivation of Liberty Safeguards Authorisation place, he was able to do many things. For example, Peter loved going out in to the community in his wheelchair or in the Care Home minibus on trips. When in the Home he loved to listen to music, and although he struggled to form words, he could make his preferences known to the staff in the Home by pointing to things and by hand gestures and the staff reported they had cared for him a long time and felt they knew him well. Peter did have physical challenges due to medical conditions, and relied on staff to help him, but would enjoy mealtimes with the support of staff.

Peter had in place a Covid Care Plan, and when he became suddenly ill with suspected Covid he was admitted to hospital. But sadly he continued to deteriorate in the hospital where it was confirmed he had Covid, and he also suffered a stroke, and despite all care he sadly died.

Introducing Richard:

Richard was a 58 year old man who had been born and lived all his life in Calderdale. His Mum described him as a beautiful boy who was a 'ray of sunshine' and who brought a lot of happiness to others. Whilst he did not have functional verbal communication, he did occasionally repeat words he had heard, including swear words and would shock staff on occasion.

He went to a special school that helped him develop some independence, and although his parents made the difficult decision to move him to a care facility, they maintained a very close relationship with him and saw him regularly, and he often went home for weekends. He moved from the Care Facility to a Supported Living Placement where he loved to go out visiting café's, and appreciated the local scenery and landscape. He also enjoyed holidays and went abroad as well as within the United Kingdom.

He had a love of Irish music and one of his holidays included a trip to Ireland. He also had other likes including football, and liked to throw and catch balls himself.

His health though began to decline, and after a series of investigations, it was found that he had a brain tumour and as his condition continued to deteriorate, he was moved to a Care Home, where he eventually died with someone always on hand to be near him.

Introducing Mark:

Mark was a 60 year old happy and gentled natured man who got on well with everyone. He particularly loved gardening and visiting garden centres was a much enjoyed trip along with going to the park or the seaside.

Mark lived most of his life with his family until he was diagnosed with Dementia. As his Dementia progressed his needs gradually increased and he needed a lot of help to the point that his needs could no longer be met at home, and he moved in to a Residential Care Home. His family though continued to visit him regularly. Despite the Covid restrictions, as his condition progressed the Home made special arrangements so that his sister could stay with him all the time and he died on a sunny day holding her hand.

1.0 Introduction and Background

1.1 The national Learning Disabilities Mortality Review (LeDeR) programme was established in 2015 / 2016 following the Confidential Enquiry into the premature Deaths of people with Learning Disabilities (CIPOLD). It was commissioned by the Healthcare Quality Improvement Partnership (HQIP), on behalf of NHS England, from the University of Bristol. It involves reviewing the deaths of all people with a learning disability to identify potentially avoidable contributory factors. LeDeR focuses on the learning that can be gained from reviewing the circumstances, in which a person with learning disabilities dies, and their care and treatment through their life.

1.2 In April 2017 CCGs took over responsibility for LeDeR from NHS England. The overall purpose of the LeDeR programme is:

- To help improve health and care services for people with learning disabilities.
- To stop people with learning disabilities dying too soon.

2.0 Purpose of this report

2.1 The NHS 2019/20 Operational planning and contracting guidance states that, to support the local delivery of the LeDeR programme, an annual report must be submitted to the appropriate board/committee for all statutory partners.

2.2 As the LeDeR programme is delivered locally via a shared team approach is led and delivered across the shared footprint, this Joint CCG LeDeR annual report has been developed to provide an overview of:

- The work undertaken locally to deliver the LeDeR reviews for local cases, including an overview of challenges to and the effect of Covid on delivery of the programme, as well as the success in deliver.
- An overview of the key information that has been gathered from local reviews including good practice and any learning
- The findings of an review undertaken nationally of LeDeR cases where the individual has died as a result of Covid- and this includes local actions to address the issues
- The work that is being delivered to transform services for people with a Learning Disability (LD)

- A brief overview of NHSE plans to change the LeDeR programme and how reviews will continue to be delivered in the future NHS architecture.

3.0 Delivering the LeDeR Programme Locally

3.1 Governance arrangements for the LeDeR programme

The CCG executive lead for LeDeR is the Chief Nurse and the programme is delivered in a shared approach by the CCG's Local Area Contact (the person who allocates cases notified to the CCG's to the reviewer, supports the reviewers, organises the quality checking process), by the Head of Nursing and Safeguarding for both CCG's, and by the Senior Clinical Commissioning Manager Continuing Healthcare (NHS Kirklees Clinical Commissioning Groups).

3.2 The Appendix A to this report provides a flowchart of the current process from initial notification of a case that requires a review to completion of the review, including the process of learning. But an overview is:

- LeDeR Team (Bristol University currently) receive notification (completed and logged on to an electronic platform by any who are aware of case – usually professionals or practitioners involved or can be family)
- Local Area Contact (LAC) is notified of the case and allocates the case to a local Reviewer
- The Reviewer accessing relevant records from health and social care (this could include such as Care Home records). And ascertains if statutory review process is underway which may result in the LeDeR review being put on hold
- Reviewer makes contact with relatives to invite them to contribute to the review.
- Reviewer completes LeDeR Review report using records and information from Carers, Professionals, Hospital Structured Judgement Reviews or other investigations and populates a report template on the electronic database that contains a total of 60 questions exploring the care and support the individual received (includes a pen portrait of the individual). The reviewer will then grade a care a person they feel the person received, recognise good practice and make any recommendations.

3.3 Once a review has been completed and submitted to the LeDeR electronic platform (hosted on a secure Bristol University site) the LAC's are notified and a quality

assurance process of the review is completed before final submission to the LeDeR system.

3.4 Linking LeDeR cases to statutory processes

3.4.1 All statutory processes take precedence over the LeDeR review including:-

- CDOP(Child Death Overview Panel: All child Deaths aged 4-17: statutory requirement Children Act 2004
- Safeguarding Children Practice Review as indicated by the Local Safeguarding Children Partnership
- Safeguarding Adults Review (SAR) as defined within the Care Act
- Serious Incident Reviews: 'adverse events, where the consequences to patients, families and carers, staff or organisations are so significant or the potential for learning is so great, that a heightened level of response is justified.'
- Police Investigations: if a crime is suspected
- Domestic Homicide Reviews: Section 9 of the Domestic Violence, Crime and Victims Act (2004)
- Deaths referred to the Coroner: to determine who the deceased person was and how, when and where they came by their death.

3.4.2 In practical terms this means the LeDeR reviewer links into the statutory process, to identify any lessons for the LeDeR review, including recognising where families have agreed to be involved in the statutory process.

3.5 Challenges to delivering the reviews in the last year

3.5.1 NHSE requirements are that a trained LeDeR Reviewer must be allocated within 3 months and the review completed within 6 months. The most significant challenge for the CCG in previous years has been limited funding to support the delivery of reviews and the majority of Reviewers continue to complete these as an addition to their substantive posts. A backlog of cases awaiting a review occurred in the previous reporting year, and whilst extensive work was underway to recruit reviewers, at the onset of the pandemic NHSE identified that LeDeR reviews could be temporarily halted in order to focus all efforts on responding to the pandemic.

3.5.2 However in June 2020 NHSE required that the reviews recommence and all backlog cases were to be completed by December 2020 (referred to as phase 1) with all future cases to be completed within the required timeframes (phase 2)

3.5.3 NHSE had provided funding to be used within areas for improving reviewer capacity in 2019, and in West Yorkshire a joint successful bid was made for some of the funds to create a small West Yorkshire LeDeR Team. Hosted in Bradford District and Craven CCG the 'central' team supported the delivery of some reviews being undertaken on behalf of the four CCG's in the West Yorkshire region. But there was recognition that the capacity of the team was limited and a combined headcount of three staff totalling 1 whole time equivalent of dedicated reviewer capacity was recruited to complete the reviews across West Yorkshire. Because of the limited capacity of the West Yorkshire Reviewer Team, the majority of Kirklees and Calderdale cases were completed by reviewers from the local area until December 2020.

3.5.4 With the support of local Health Providers and Local Authority partners a shared approach across Calderdale and Kirklees to complete the reviews was undertaken with success, as all backlog cases for the two areas were completed by December 2020:-

- a total of 28 backlog cases reported before July 2020
- further 8 cases completed that had been reported in the rest of 2020
- All new cases from January 2021 have been allocated a reviewer and many reviews have been completed, within only those awaiting a statutory investigation awaiting the completion of an LeDeR review.

3.6 West Yorkshire LAC approach

3.6.1 In order to provide a supportive approach from July 2020 the Local Area Contacts from the West Yorkshire footprint met fortnightly to review progress, support progression and to sharing any learning or approaches to delivering the programme including the backlog

3.6.2 There was significant learning from this approach including:

- LAC's working together to problem solve and plan despite the challenges of representing different CCG's with differing priorities.

- The lead for the hosting service felt well engaged with and supported by the Local Area Contacts.
- The dedicated Reviewer resource in the West Yorkshire Team delivered reviews to a high standard
- The development of a central administrator post within the West Yorkshire Team meant that reviews could be coordinated and clinical information could be requested on behalf of the reviewer.

4.0 LeDeR reviews locally

4.1 The number of Local Cases

Table 1 below details all deaths of people with a Learning Disability to each CCG reported in the last year

Table 1

CCG	Total notifications for year 2020-2021	Notifications received in year 2019-2020
NHS Kirklees CCG	21	22
CCCG	8	17

Table 2 identifies how many LeDeR reviews the CCG's were notified to the CCG's and were completed within the year

Table 2

CCG	Total notifications for year 2020-2021
NHS Kirklees CCG	13
Calderdale CCG	5

Table 3 Details the LeDeR reviews that were reported but have not yet been completed and the reasons for the delay

CCG	Child Death Overview Panel (CDOP) Report	Statutory investigation (e.g. Coroner, Police or Safeguarding Adults Review)	Reviews awaiting completion (within 6 months required timeframe set by NHSE)
NHS Kirklees CCG	3	2	3
NHS Calderdale CCG			3

4.2 Completed LeDeR reviews in the last year

4.2.1 In total there have 18 completed LeDeR reviews for Calderdale and Kirklees in the last year, and all were quality assured by the CCG LAC'S before submission to the LeDeR Programme. The following provides a combined overview of the findings from the completed reviews. But it is recognised that those Reviews that were notified to the CCG's but have not yet been completed (and not quality assured) have not been included in this section, and do have the potential to alter the information provided, findings and learning in this section.

4.3 Demographics for cases

4.3.1 Gender

Table 4

	Females cases	Male cases
Total	6	12

4.3.2 Ages of those who died

The age range of deaths for completed reviews is detailed in table 5. This does not include the ages of children who died as these cases are still under a statutory CDOP processes and have not yet completed.

It is of note that 55% of adults reviewed died between the ages of 50- 69.

Table 5

Age	18-29	20-39	40-49	50-59	60-69	70-79	80 and above
Combined CCG	2	1	2	4	6	1	2

4.4 Key information about the Death

4.4.1 Cause of Death

Of the principle causes of death from completed reviews it must be noted that many had more than one cause of death or other co-morbidities that may have contributed to the principle cause of death. Covid or suspected Covid account for the largest cause of death, with deaths due to other reasons all small, making thematic analysis more difficult. The combined causes of death for the CCG cases are:

- Aspiration pneumonia (1 case)
- Multi-organ failure (with pneumonia) (1 case)
- Covid/Covid suspected (5 cases or 27.77%)
- Bronchopneumonia and CCF (1 case)
- Pulmonary Thromboembolism (1 case)
- Cardiac (1 case)
- Advanced end stage dementia (1 case)
- Cerebral Vascular Accident (1 case)
- Bowel Ischaemia and Sigmoid Volvulus (2 cases or 11.11%)
- Cancer/brain tumour – incurable (3 cases or 16.66%)
- Epileptic fit and cardiac arrest at home (1 case)

4.4.2 Multi morbidity

The presence of multi-morbidities has the potential to impact markedly on the quality of life and could result in poor health outcomes dependent on type and severity.
The NICE Guidelines about clinical assessment and management of multi-morbidity defines it as the presence of two or more long-term health conditions, which can include:

- Defined physical and mental health conditions such as Diabetes or schizophrenia.
- Ongoing conditions such as a learning disability.
- Symptom complexes such as frailty or chronic pain.
- Sensory impairment such as sight or hearing loss.
- Alcohol and substance misuse.

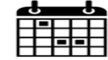
Of the 18 people who had a LeDeR review completed, all cases had more than 2 long-term health conditions in addition to having LD. A total of 17 cases (94%) had 3 or more long term health conditions in addition to LD.

Table 6: Multi-morbidities (excluding LD)

Multi-morbidities	2	3	4	Above 4
Total number of individuals	1	9	3	5
Percentage	5.5%	50%	16.665	27.77%

The most commonly reported long-term health conditions were (other conditions were also identified but these accounted for less than 10% of cases):

- Epilepsy: 55% of the cases
- Cardiovascular disease (e.g. Ischaemic Heart Disease, Myocardial Infarction, Stroke, Hypertension, Transient Ischaemic Attacks): 44% of cases
- Mental Health issues (e.g. Mood disorder, Schizophrenia, Paranoid depression, global development delay) = 44% of cases
- Sensory Impairment (blindness, deafness) = 44% of cases
- Gastro-intestinal conditions (e.g. Gastric Reflux, Ulcerative Colitis) 38% of cases
- Obesity: 22% of cases
- Dementia:16% of cases
- Respiratory (e.g. chronic disease, long term ventilation): 11% of cases
- Hypothyroid: 11% of cases

4.4.3 Month of death 

There was a rise of the deaths in April 2020 which coincides with the start of the pandemic, and 4 of the 5 deaths due to Covid occurred in April 2020, with the other death due to Covid occurring in early May 2020. This increase mirrors the national picture with the Government reporting a rise in the national death rate of 20% above average from March – April 2020, although of note the local LeDeR reviews suggest a higher number within the LD population in Kirklees and Calderdale.

Table 7: LeDeR cases deaths by month

Month	Numbers
January	1
February	0
March	0
April	6
May	2
June	2
July	2
August	1
Sept	2
October	2
November	0
December	0

4.4.4 Place of Death

The place of death for the 18 reviews notified and completed during the year was evenly split with half dying in hospital and the other half dying in their usual place of residence.

4.4.5 End of Life Care planning

It is of note that 66% (a total of 12) of those who died had in place an End of Life care plan suggesting good practice, 5 individuals who died unexpectedly, and just one individual where it was recognised that a plan should have been in place but wasn't.

Table 8: End of Life Care Plan

	Had a plan in place	Should have been a plan in place but was not	The death was unexpected	The individual was on a gold standards palliative care Framework/or had both
Total	10	1	5	2

4.5 Finding themes

4.5.1 Overall assessment of care

On completion of every case, the reviewer makes an assessment of the level of care provided on a range from 1 (excellent) to 6 (care fell far short of expected good practice).

The table below shows the overall definitions and grading of care provided to the 18 individuals. Table 9 demonstrates that 94% of cases was assessed as level 3 (satisfactory care) or above with only 1 case following below the marker of acceptable care. For this one case the issue was due to the failure to fully monitor and evaluate the individuals Bowel Care Plan which had some impact on the individual's quality of life. The learning was taken forward by the organisation involved.

Table 9: Assessment of Care level

Level of care	Case Numbers	Percentage
Level 1: This was excellent care and met current best practice	**4**	**22.22%**
Level 2: This was good care, met expected practice	**9**	**50%**
Level 3: This was satisfactory care (it fell short of expected good practice in some areas but this did not significantly impact on the person's wellbeing).	**4**	**22.22 %**
Level 4: Care fell short of expected good practice, this did impact on the person's wellbeing but did not contribute to the cause of death.	**1**	**5.55 %**
Level 5: Care fell short of current best practice in one or more significant areas, although this is not considered to have had the potential for adverse impact on the person some learning could result from a fuller review of the death.	**0**	**0%**
Level 6: Care fell far short of expected good practice and this contributed to the cause of death.	**0**	**0%**

4.5.2 Positive themes

There were a number of positive themes from the completed reviews.

<u>Reasonable adjustments</u>

The reviews found that in all cases reasonable adjustments had been found to support the individual examples include:

- Hospital visiting rules during the pandemic were changed for the individual to allow one member of family to continue to visit throughout the hospital stay with supportive arrangements in place for family including parking costs

- Health care professionals (e.g. General Practitioners, Therapy Staff, Dietician, Specialist Nursing Services) visited the individual rather at their residence as travelling to appointments was difficult
- Hospital LD passport used well to support staff understanding of the individuals needs and preferences
- Health appointments sent to the individual and their Carer/Relative so they could support the individual with LD, and Carers attending appointments to provide support
- For one individual General Practitioner (GP) Practice ensured same GP always saw individual, to build Trust and in depth knowledge of person

Annual Health and Annual medicine checks

Table 10

Positive Theme	Detail
Annual Health Checks	12 individuals had annual health checks in place with valid reasons why this had not occurred in 2 cases.
Annual Medication Checks	17 individuals had annual medication checks

Other Good Practice examples

There were a number of good practice examples within LeDeR reviews. Some examples include:-

- Proactive discussions of end of life and DNACPR to assist should an acute medical emergency occur in some cases
- Complimentary therapy was provided in the hospice to alleviate anxiety at end of life.
- There was a clear record of person centred approaches being implemented which kept the individual and his sisters wishes at the heart of his treatment
- Structured Judgement Review undertaken by provider of care (care home) after the individual died- which resulted in a plan for staff learning and development
- The health service in the community appeared to be seamless with any areas of need identified, being actioned quickly.

- It was noted from family/main carer feedback that the experience of the funding/commissioning process was excellent and they found no issues in obtaining the right level of support based on the individual's needs.
- The use of the non-verbal DIS DAT tool to help the person with LD communicate with others
- Good use of the Pepsi Cola Aide Memoir as Gold Standard Framework for his end of life Care.
- Good regular contacts by Epilepsy Specialist Nurse and Neuro Consultant service - especially noted at how quick they were to contact family following each hospital admission to discuss findings and how quick they acted in making changes to medications and involving parents in all aspects of their service.
- Team work with nursing home, GP, DN and specialist palliative care nurse, proactive support especially during COVID pandemic
- Noted on GP Care Summary that individual had mental capacity and that his preference was for core items only to be included on his care records summary. So only this detail used as part of reviews.

4.5.3 Learning from local cases

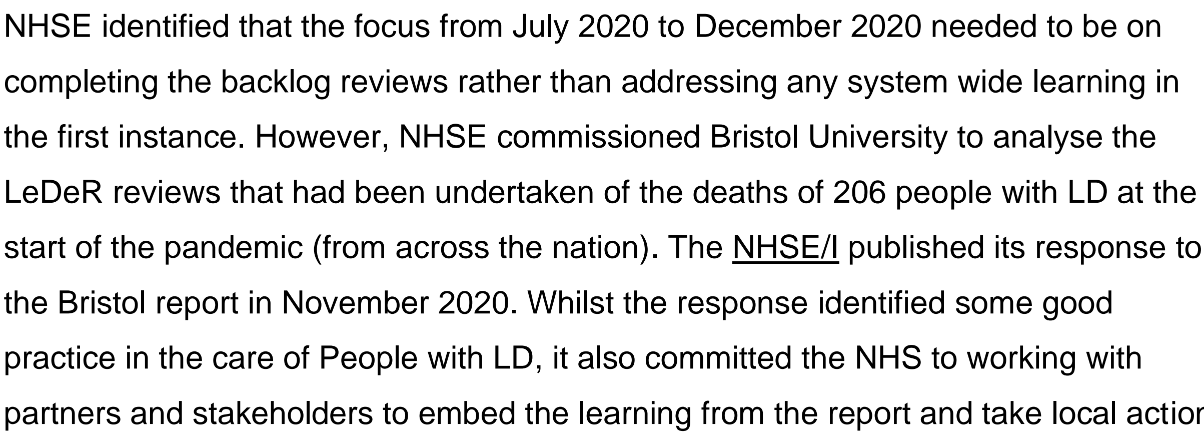
Examples of areas for improvement for learning and recommendations by reviewers include:-

- Identification of Down's Syndrome as secondary cause of death raises concern about prejudicial attitude about inevitability of premature death and possible inaction to address risk factors effectively
- Recording and monitor bowel movements and bowel management planning (
- Consider training for some providers regarding recognising the deteriorating patient to support their practical care and support planning (
- The policy and procedures relating to Do not attempt Cardio-pulmonary Resuscitation (DNACPR) and involving family in discussions around resuscitation or in a timely way
- Hospitals to consider making provisions to ensure that people with learning disabilities are supported and reviewed by the liaison nurse to ensure they receive adequate and appropriate support

- Limited or no evidence within the health care record received of Mental Capacity Act assessments or considerations in relation to care and treatment decisions
- The GP Practice acknowledged that they could have pursued further to establish formal diagnoses. There were three opportunities missed to ensure a formal assessment and diagnosis of LD was made
- Annual LD review could consider and document whether specialist LD services are involved and if they should be?
- Nursing staff did not explain processes or consider the needs of the carer at the death of the patient resulting in distress and trauma

5.0 Taking forward learning from cases

5.1 National Learning from deaths due to Covid



NHSE identified that the focus from July 2020 to December 2020 needed to be on completing the backlog reviews rather than addressing any system wide learning in the first instance. However, NHSE commissioned Bristol University to analyse the LeDeR reviews that had been undertaken of the deaths of 206 people with LD at the start of the pandemic (from across the nation). The NHSE/I published its response to the Bristol report in November 2020. Whilst the response identified some good practice in the care of People with LD, it also committed the NHS to working with partners and stakeholders to embed the learning from the report and take local action under 4 key priority areas:

- Key priority area 1: Identifying deterioration in health.
- Key Priority area 2: Do not attempt cardiopulmonary resuscitation (DNACPR) and learning disability as a cause of death
- Key priority area 3: Diagnostic overshadowing
- Key priority area 4: Reasonable adjustments

5.1.2 Local Actions to respond to LeDeR learning

Priority 1: Identifying deterioration in health

Actions to improve the detection of deterioration in the health of people in community and home settings including people with LD include:

The primary care network (PCN) contract 2020 requires every care home in England will now have a lead GP with overall responsibility for delivering the ‘Enhanced Health in Care Homes’ (EHCH) service requirements. This framework published in March 2021 provides guidance for primary care and community health services to ensure that people living in care homes receive the same level of access to healthcare and support as they were when living in their own home; and moves towards proactive care that is centred on the needs of individual residents, their families and care home staff.

In both Calderdale and Kirklees all homes for people with LD have a lead GP and care coordinator that is working closely with the home to ensure reactive and proactive needs are being met in a timely manner. Calderdale CCG and Kirklees CCG have held sessions with staff representatives from care homes for people with LD and Kirklees CCG presented at the Kirklees Provider Forum, to discuss the model and its aims. The aim is for the Learning Disability Health Checks and Health Action Plans to be completed and used as the personalised care plan for people.

In support of the delivery of EHCH requirements it has been agreed to recruit to a new matron post In Calderdale. This post will be a hybrid combining the nursing skills of general and learning disability nurses and builds upon the established care homes matron led service. It will provide a proactive service regarding physical health into the LD care homes, working closely with the Community Learning Disability Team (CLDT), the acute trust and primary care. Interviews take place early June with an ambition to have someone in post by August 2021.

A provider workshop held in January 2021 focussed on Annual Health Checks (AHC) and how staff can support people to access and prioritise these and to embed details from Health Action Plans (HAP) into individuals care and support plans. This will be followed by a subsequent event to be held in April 2021 to share learning and best practice and future sessions are planned.
Kirklees CCG commissioned a Health Facilitator post to support the PCN’s and Care in prioritising and supporting people access to Annual Health Checks and health actions plans and ensuring the outcomes/actions were embedded in the Individual care and support plans.

Representatives of Kirklees CCG and SWYPFT attended the PCN Development Meeting in June to deliver a presentation on the evaluation of the first 6 months of this role and the proposed developments for the Roles and Responsibilities of the Strategic Health Facilitator post, Annual Health Checks and Health Actions Plans and collaborative working with the PCN's.

An interim service has been commissioned from South West Yorkshire Partnership Foundation Trust (SWYPFT) Community Learning Disability Team (CLDT) to support the completion of AHCs 20/21, dedicated team of two LD nurses reaching out to people in their 'own homes' and doing a qualitative review and AHC. Feedback so far has been very positive that people feel more comfortable and able to have meaningful and open conversations in their own homes. Learning from this new approach will inform expectations of the approach to delivery of AHCs 21/22.

Cloverleaf Advocacy and an expert by experience are working with us to support hard to reach individuals to access AHC's and to support professionals to deliver reasonable adjustments. There is also work at Transforming Care Partnership (TCP) level across Calderdale, Kirklees, Wakefield and Barnsley which includes Healthy Living Group, promoting healthy lifestyles and the importance of AHCs.

The Continuing Health Care Review template has been redesigned to have a particular section for people with LD to check that people have up to date AHCs, HAPs and screening tests. Issues identified will then been escalated back to the PCNs for action.

The joint CCG's Quality Team have offered supportive training sessions to Care homes in Calderdale and Kirklees in how to recognise signs of deterioration in their residents through the use of 'Soft signs' . Soft signs can be assessed by carers who know a resident well and recognise subtle changes to usual behaviours when a person is becoming unwell. The training also guides on concise, clear communication on findings to relevant healthcare professionals to access early clinical review.

The Local Authority Infection and Prevention Control Team (IPC) are supporting LD homes with IPC training and ongoing audits of compliance which has also been well received.

Calderdale and Huddersfield Foundation Trust (CHFT) have created a learning disability dashboard to monitor a series of specific concerns related to health including 'did not attend rates' to Outpatients of people with LD and other concerns. The Dashboard continues to be developed and will next include Emergency Department attendances, In-patient data and Outpatient referrals deep dive took place from April 2020 and this was reported to safeguarding committee.

The SWYPFT LeDeR coordinator and the Clinical Lead have in place a strategic action plan for LD and the organisation has introduced a new Advanced Respiratory Care Practitioner and is continuing to the roll out of News2 (National Early Warning Score, an early warning system to help staff identify individuals who are becoming acutely ill). The Trust is also currently rolling out the Covid19 vaccination programme to Leaning Disability Inpatient wards and has a plan to support patients in our community teams to access the vaccination. Alongside this, additional medical devices have been purchased to facilitate the earlier identification of recognising a deteriorating patient and staffs have undertaken additional training around the appropriate use Oxygen.

Priority 2: DNACPR and learning disability as a cause of death

GP practices have been asked via the Quality and Outcomes Framework to review all DNACPRs for people with a learning disability registered with their practice and confirm that they were determined appropriately and continue to be clinically appropriate. This is included in the primary care/ GP contract for 2020-21.

This is an explicit requirement within the health check. In Calderdale and Kirklees additional support has been funded for General Practice to increase the number of health checks for people with a learning disability. The aim was for 75% of health checks to be completed by the 31st March 2021 with the additional support reaching those who normally do not engage with the process and encouraging standardisation of process. These health checks include a review of any DNACPR decision to ensure it was and remains clinically appropriate.

CHFT are in the process of planning to undertake an audit of all DNACPR forms to ensure correct and accurate usage. An additional question has been added to the

audit process undertaken by the Trust LD Matron to check that reasonable adjustments are in place specifically about DNACPR.

Priority 3: Diagnostic overshadowing

In July 2020 a letter was sent to NHS system leaders setting out actions to tackle inequalities, including the prioritisation of annual health checks and vaccinations for people with a learning disability in the coming months.

In Calderdale additional support has been funded to assist General Practice to complete health checks and monitoring of flu vaccination uptake for people with a learning disability at practice and CCG level. Messages have also been shared to encourage practices to make every contact count and either vaccinate as part of the health check or support the person to book an appointment for a vaccination.

GP practices across England have been asked to use their clinical judgement to determine who, on their GP register, should be considered at a higher risk of serious illness from COVID-19 and to take appropriate action to advise those individuals and their carers (as appropriate) of the need to take additional precautions.
In Calderdale this requirement has been highlighted through key messages including the need for practices to add people with Down's syndrome to the clinically extremely vulnerable cohort.

In addition GPs have been reminded about the risks of diagnostic overshadowing in people with a learning disability and that the presentation of people LD and who have contracted COVID-19, or another condition which causes health to rapidly deteriorate, may be different to the general population, so that people with LD are not overlooked in terms of access to appropriate and timely health care.

The new LD community matron and Strategic Health Facilitator role will be key to helping providers to recognise early symptoms of ill health and the link with changes in behaviour. They will be able to action any concerns, working closely with the CLDT. Work with providers has started through a recent workshop to be confident in recognising the possibility of physical health issues linked to behaviour and ensuring that they get access to the right support form health services. For care homes the

relationship with the new care coordinators is a key part of this as they are accessible and will have good relationships with care homes.

In Calderdale the CCG shared the University of Bristol report looking at the deaths of 200 people with LD who died between 2 March and 9 June 2020 along with the NHSE response “Action from learning response to learning from deaths of people with a learning disability (LeDeR) review of COVID pandemic deaths.” The message included a brief learning summary for GPs in relation to diagnostic overshadowing with three actions that can be taken to diagnose and treat respiratory disease at the earliest opportunity.

Priority 4: Reasonable Adjustments

There is a programme of joint training from CLDT and Cloverleaf with GP practices re understanding and putting in place reasonable adjustments. An example of changes that have been made is adaptations to make external doors more accessible at one of the Lower Valley practices.

Cloverleaf Advocacy and an expert by experience are working to support hard to reach individuals to access AHCs and to support professionals to make reasonable adjustments they need to access AHCs. These might include longer appointments, easy read information prior to the appointment or a home visit.

Work has been undertaken with providers to ensure their knowledge of individuals is shared with key professionals i.e. hospital via VIP passport and GPs through AHCs to ensure people receive a comprehensive and seamless approach to their health and social care support. This might include detailed information about communication, support preferences and other reasonable adjustments required to successfully support someone needing to access medical support.

COVID Vaccination: When the Government announced its national vaccination programme, the priority groups did not include people with a Learning Disability. This meant that although some people were able to access a vaccination because they were in another priority group (for example due to underlying health conditions), others would not be able to access the vaccination until it reached their age group.

The CCG's wanted to make sure that everyone with LD was able to receive a vaccination as a priority and set up a multi-agency group to make this happen. Shortly afterwards, the Government announced that one of the priority groups would be extended to include everyone with a Learning Disability.

Primary Care Networks worked hard to enable as many people with a learning disability as possible to access their local vaccination clinics, in line with the local approach of supporting people with a learning disability to access mainstream services where possible. However, it was recognised that some people needed a more personalised approach and the CCG's has been leading work to put on bespoke clinics in the PCNs for people with LD.

In March, CHFT ran a weekend cinema-style experience with films, music and refreshments for people with learning disabilities .Thirty people with learning disabilities attended and received their vaccination in a safe and relaxed environment.

6.0 Other Transforming Care work over the last year

6.1 A project to develop and implement an enhanced all age Dynamic Risk Register for people with Autism, to ensure any change or potential risks of an individual's Autism or Mental Health is identified at an early stage and that interventions are provided by the Local Community Teams and reviewed regularly and reducing the risk of hospital admission.

6.2 Development and implementation of a single Care Education and Treatment Review (CC(E)TR)) Hub for Calderdale, Kirklees, Wakefield and Barnsley ensuring that C(E)TR's are arranged and completed in a timely manner and that the relevant clinical teams are in attendance to support individuals.
This also facilitates the mandated reporting for NHS E.

6.3 During COVID 19 Lockdown, CTLD undertook a weekly call to all LD Care Homes to support the delivery of EHCH requirements and to identifying and responding changes in individual's behaviours and mental health.

6.4 Ongoing work with service user representatives, the CCGs involvement networks and Inclusion North to develop a web based information portal for both professional and

our populations to access up to date and easy read information, to support them to deliver accessible health care to our learning disabled and autistic populations. The information is updated following feedback on the theme emerging from LeDeR reviews.

6.5 Members of the TCP board developed specific chapters for Learning Disabilities and Autism, including the completion of demographic mapping for each area's published Joint Needs Assessment. They also supported work with Business intelligence colleagues to develop information to be included within the PCN data packs. This work supported the development of key learning disability / autism indicators for inclusion within the primary care dashboards.

6.6 Health Inequalities mapping has been undertaken during quarter 4 20/21 to support the development and implementation of a local TCP level action plan during 21/22. This work has been amalgamated with the wider west Yorkshire plan to ensure improvements and learning are delivered at scale.

6.7 Through-out the pandemic C(e)TRs have been conducted both virtual or face to face. The CeTR hub has been reviewed & a new single 'drive' with access to secure documents is being established, a standard operating procedure (SOP) has now been reviewed to reflect both adult and CYP pathway. We ensure that advocacy is part of any CeTR.

6.8 Across the TCP a consistent Adult Autism Pathway has been implemented, this delivers a 13 week full assessment and diagnostic pathway. Within Kirklees the integrated commissioned pathway also delivers Post Diagnostic intervention. In addition the Kirklees system have also commissioned Voluntary Sector organisation to provide 'Autism Engagement' service to provide social skills training opportunities for adults with Autism across the district and a supported employment programme specifically tailored towards adults with Autism to increase the confidence, employability and overall health and wellbeing.

7.0 Future planning and Priorities for the LeDeR Programme

7.1 New NHSE LeDeR Policy

7.1.1 NHSE published a LeDeR policy on the 23rd March 2021 with marked changes for the future programme identified, including the commencement of reviews for people with Autism as part of the programme later in the year

7.1.2 Firmly stating that the LeDeR programme must be seen as a Quality Improvement Programme the policy identifies strict timescales for implementation for different elements (start from June 2021). Key headlines include:-

- Integrated Care System (ICS) to develop a 'dedicated resource' reviewer team (see below) who will be responsible for ensuring LeDeR reviews are completed and actions implemented to improve quality of services to reduce health inequalities and premature mortality - local governance arrangements should feed into local quality surveillance groups and, health and wellbeing boards
- ICSs must systematically act on findings via a land measure the impact of LeDeR and will be held to account by NHSE for delivery of actions as part of their assurance process (actions are robust, address the issues identified and will achieve the objectives required, and ensure that ICSs report on performance against the actions agreed for all reviews completed)
- Quality assurance - LeDeR **must** be incorporated into the routine quality reporting arrangements of the ICS and at a local level - not to sit separately from it.
- Clear and effective governance in place which includes LeDeR governance within mainstream quality surveillance and governance arrangements - plan by 30 September 2021, operational by 1 April 2022
- ICSs need a clear plan in place by 30 September 2021 for new QA structures and processes for LeDeR to be operational by 1 April 2022 - agree how QA during transition
- An annual ICS LeDeR report demonstrating how the ICS is delivering on local actions. The annual report will be published in June each year and will be taken to a public meeting of CCG/ICS/HWB. It will demonstrate effective delivery of actions from learning from LeDeR reviews by 30 June 2021 and then annually

- A three-year LeDeR strategy demonstrating how the ICS will act strategically to tackle those areas identified in aggregated and systematic analysis of LeDeR reviews and national findings including how the ICS will reduce the health inequalities faced by people from Black, Asian and Minority Ethnic communities who live locally who have a learning disability by 30 June 2021.

7.1.3 LeDeR Reviewers

- The ‘dedicated resource’ reviewer team - must include Senior reviewer role with oversight of review team capacity with regular supervision and administrative support - close enough to the ICS to understand how it operates (i.e. which providers and commissioning landscape), but still independent from providers.

7.1.4 Quality Assuring LeDeR reviews and actions

ICSs will establish a local place based governance groups which will sign off focused reviews and agree SMART actions which feed into the strategic plan for the local area
ICSs will establish a local governance group/panel which will sign off focused reviews and agree SMART actions which feed into the strategic plan for the local area.

The panel will consist of people who have responsibility for the quality of services and can take action to improve services, and must include people with lived experience

7.1.5 Delivery expectations

- A robust plan will be in place to ensure that reviews are completed within six months of the notification of death - by 30 June 2021
- Each quarter all actions from LeDeR reviews will be considered and progress on delivery will be reported to the NHS England and NHS Improvement regional team - from 30 September 2021
- ICSs will demonstrate how they are narrowing the gap in health inequalities and premature mortality for those who have a learning disability in their local area by 30 June 2021
- Clear and effective governance in place which includes LeDeR governance within mainstream ICS quality surveillance and governance arrangements - plan by 30 September 2021, operational by 1 April 2022

- A named executive lead as SRO with accountability for LeDeR across the ICS - 30 June 2021
- A named lead with responsibility for Black, Asian and Minority Ethnic inequalities within local Governance arrangements - 1 April 2021
- Clear strategy for meaningful involvement of people with lived experience in LeDeR governance - 30 September 2021
- Senior ICS leaders, including local authority partners are involved in governance meetings where issues found in local reviews are discussed and actions agreed collaboratively, to support joined-up actions to improve services, reduce health inequalities and reduce premature mortality - 1 April 2022

7.2 Priorities for the coming year: Delivering the new LeDeR Policy

7.2.1 Discussions and work is currently underway to deliver on the new policy involving ICS Transforming Care Lead, current Local Area Contacts (under the new policy there will only be 1 LAC for the ICS), and Chief Nurse leading on behalf of the ICS.

7.2.2 The work needed to deliver the policy includes:

- Further development and an increase in capacity of the West Yorkshire Team of Reviewers to undertake all the LeDeR Reviews for the West Yorkshire and Harrogate Partnership
- The delivery of a single LAC for the ICS
- The development of an ICS Steering Group to oversee the reviews completed and make recommendations
- A local based group to develop and take forward any actions identified from the Reviews, this will include embedding the learning as part of quality processes for improving care.

7.2.3 The annual report for the CCG provides one requirement of the NHSE policy, but from April 2022 the requirement will be for an overall ICS LeDeR annual report that will include an overview of the programme both from an ICS and from a local place based perspective.

Appendix A Part 1: Flowchart from notification to learning: process current

Central LeDeR Notifications

- LeDeR team receive notification of death
- Identify those meeting criteria for review

Inform and assign cases for review

- LeDeR team informs Local Area Contact (LAC) of new case
- LAC identifies reviewer and informs LeDeR
- LeDeR team informs reviewer of the case allocation

Reviewer receives notification of allocation of review and:

- Requests copies of person's records (e.g. Medical records from GP. Hospital records, care home records) - Identifies if the individual subject to any other existing statutory review process (E.G. SAR, Coroner inquest?

YES

Reviewer links with other review process

- Establish nominated contact for other review
- Liaise with nominated contact
- Collect core data for LeDeR review

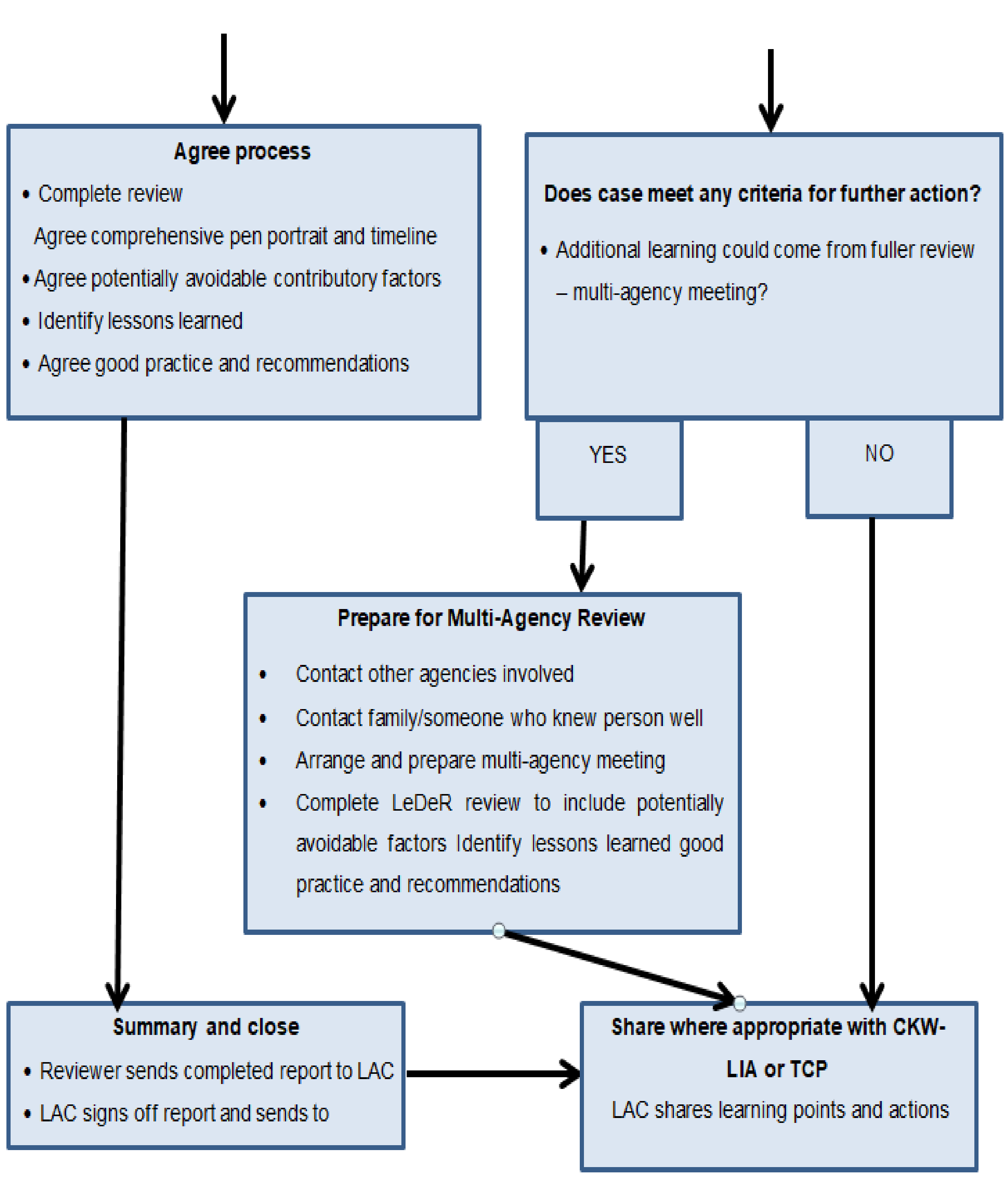
** Of note CDOP cases do require LeDeR reviewer allocation – CDOP reports are reviewed by LAC and submitted to LeDeR system

NO

Reviewer completes review including

- Conversation with someone who knew person well – family may want to contribute and so meetings to be arrange and their views included
- Review of relevant records
- Complete pen portrait, timeline and other details
- Any learning or recommendations identified

Appendix A Part 2: Flowchart from notification to learning



(This may not be fully accessible to some assistive software but the information can be provided in a more accessible format on request)